MOTOR (PHYSICAL) CHANGES IN LEWY BODY DISEASE

Lewy body disease is a common neurodegenerative disease of ageing that is considered to be a spectrum disease. The disorders in the spectrum are: Dementia with Lewy bodies, Parkinson's disease and Parkinson's disease dementia

One of the most confusing aspects of Lewy body disease is the relationship between the disorders in the spectrum and their impact on body movement. Traditionally, Parkinson's disease is described as a progressive disease which affects the control of body movements. However, it is important to understand that Parkinson's is not just a motor disorder. People with Parkinson's can also experience changes in their thinking, mood, behaviour and autonomic functions (involuntary functions like temperature control). Most people with late onset Parkinson's disease eventually develop Parkinson's disease dementia.

Typical motor changes

There are subtle differences in the motor deficits seen in people classified as having dementia with Lewy bodies compared with those classified as having Parkinson's disease.

In Parkinson's disease, the four most common motor symptoms are tremor, rigidity (muscle stiffness), postural instability (difficulty maintaining posture and balance) and bradykinesia (slow movement). Symptoms often begin on one side of the body only and people respond well if treated with dopamine replacement therapies (e.g. levadopa).

People with dementia with Lewy bodies tend to demonstrate more rigidity of their torso, and more balance problems than those with Parkinson's disease. On the other hand, they tend to have less tremor, are affected (or non-affected) equally on both sides of their bodies, and have a less dramatic response to dopamine replacement therapies.

Recognition of these differences from Parkinson's disease is important to avoid misdiagnosing dementia with Lewy bodies as Parkinson's and potentially missing out on the most appropriate treatments.

Other motor factors

People with Lewy body disease are at increased risk of falls when challenged by uneven surfaces, steps and stairs because of their motor problems coupled with their visuospatial deficits (see Sheet 2: Cognitive Changes).

Lack of motor control is compounded by fluctuations. Walking may be an ideal leisure activity one day and seemingly impossible on another.

An autonomic (involuntary) deficit called orthostatic hypotension results in a person losing the ability to automatically regulate their blood pressure. Blood pressure drops (often when standing up) and they appear to 'collapse at the knees' - increasing the perceived fall rate and the burden of care.

Motor deficits associated with speaking and swallowing may also occur. Speech may become slower and less fluent and swallowing is less frequent. These deficits become more evident as the disease progresses and can include loss of the gag reflex which may lead to aspiration and pneumonia.

Managing physical or motor changes

Movement disorder clinics and allied health professionals with expertise in treating people with Parkinson's disease can assist in the assessment and management of many of the physical challenges that people with Lewy body disease face. Contact the local Parkinson's organisation for advice. The strategies on the next page have been sourced in part from parkinsons.org.au

FIGHTDEMENTIA.ORG.AU

NATIONAL DEMENTIA HELPLINE 1800 100 500

Maintain mobility & independence

Physical activity should be maintained and encouraged within the limits of the person's ability and fluctuating state. On a good day going for a walk with a family member or friend is perfect. Gym membership can be maintained – talk to the staff.

Fine motor skills and movements to command (such as 'lift your leg' when assisting dressing) can be difficult.

- Encourage good posture by conscious attention and daily stretches.
- Encourage and join in an enjoyable exercise routine.
- Encourage the wearing of appropriate footwear (closed with flat or low heels, velcro tabs, no laces).
- Provide alternatives to small buttons.
- Encourage independence for as long as possible.

Reduce the risk of falls

Falls may occur for many reasons including balance problems, low blood pressure, a shuffling walk, turning corners or dual tasking. Avoiding falls is essential. Serious injuries such as fractures (commonly hip or skull) may result. The fear of falling and associated loss of confidence may be as disabling as an actual fall.

- Remove unnecessary mats.
- Maintain an uncluttered environment.
- Move slowly from lying or sitting positions and remain by the bed or chair for a short period of time.
- Report dizziness on standing to your GP as this may indicate orthostatic hypotension.
- Consider aids such as hip protectors.

Speech and swallowing problems

Swallowing changes are usually gradual. However, if frequent coughing or spluttering occurs, assessment by a speech pathologist is essential. A video-fluoroscopy is a commonly used investigation to assess swallowing.

- Correct posture is vital for safe swallowing. A straight back (if possible) and a slightly forward head position is the safest option.
- Avoid dual tasking such as eating and talking or reading. Chew and swallow each mouthful before taking the next. A second swallow may be needed.
- Consider thickening fluids.

Aids and Equipment

A physiotherapist can assess if a walking aid is required. This will ensure that an appropriate aid is issued, e.g. a walking frame.

An occupational therapist can assess the safety of the home environment. Appropriate chairs, equipment and rails will help to maintain independence and safety.

FURTHER INFORMATION

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at **fightdementia.org.au**



For language assistance phone the Translating and Interpreting Service on **131 450**

Resources

Parkinson's Australia is the peak body for advocacy and support of people with Parkinson's disease. Visit **parkinsons.org.au** or call **1800 644 189**. US Lewy Body Dementia Association visit **Ibda.org** UK Lewy Body Society visit **lewybody.co.uk**